

*Next Meeting – February 25, 2008 – 1:30 PM  
DE Public Archives, Dover*

**STATE COUNCIL FOR PERSONS WITH DISABILITIES  
FULL COUNCIL MEETING MINUTES**

January 28, 2008 – 1:30 PM  
Appoquinimink State Service Center  
Middletown, Delaware

**MEMBERS PRESENT**

Rita Landgraf, Vice Chair; Tom Barlow, Easter Seals; Susan Cycyk, DSCYF/CMH; Kathy Goldsmith, DOE; Brian Hartman, DLP/DDC; Bonnie Hitch, DTC; Tony Hortsman, Parent; Jim Lafferty, Mental Health Association; Don Moore, CAP; Dan Muterspaw, AAB; Carolanne O'Brien, DOL/DVR; Bob Osgood, Past Chair; Loretta Sarro, DODHH&CODHHE; Liz Schantz, Consumer; Wendy Strauss, GACEC; Ginger Stein, MS Society of DE; Sandy Tuttle, Easter Seals; Kyle Hodges, Staff and Linda Bates, Support Staff

**MEMBERS ABSENT**

Daniese McMullin-Powell, Chair; Cookie Austin, Parent; Brian Bard, Consumer; Regina Byers, GCAAPD; Norwood Coleman, Sr., Consumer; Lisa Furber, State Rehabilitation Council; Connie Hughes, DelARF; Janet Leitch, Consumer; Christine Long, DDDS/DHSS; Ann Phillips, Parent; and Dennis Rubino, DHSS/DPH

**GUESTS**

Rob Gilsdorf, President of the DE Autism Society/Delaware Disability Advocacy Coalition  
Dr. Tim Brooks, Board President of ARC/DE  
Kamisha Martin, Nehemiah Gateway-DE EITC  
Margaret Bailey, DNHRQAC  
Marie Eldreth, MS Society of DE;

**INTERPRETER**

Lois Steele

**CALL TO ORDER**

Rita Landgraf called the meeting to order at 1:35 pm.

**ADDITIONS DELETIONS TO THE AGENDA**

- Medicaid Buy-In Update is deleted from today's agenda; however, it will be added to the February agenda.
- The Navigator Program is being added.
- Jamie added a CMS rule on Personal Attendant Services
- Tom Barlow will give an update on PAS Services.
- MFP update will be given by Jamie or Kyle.

## **APPROVAL OF MINUTES**

Motion was made, seconded and approved to accept the October 15, 2007 meeting minutes as submitted.

## **Delaware Disability Advocacy Coalition**

Rob Gilsdorf gave the following update of the activities of the Delaware Disability Advocacy Coalition. A hand-out was also distributed from the Delaware Advocacy Coalition for the Family Support Waiver.

Rob is a father of a 17 year male with autism. Rob has been president of the Coalition for a few months but has been involved for years. Within the Autism Society of DE, Rob was chair of the Legislative Advocacy Committee and through that work he worked closely with legislators in the State of DE to pass legislation for the Autism Registry and worked with other people in the state to get legislation passed prohibiting the use of the thimerosal in vaccines which went in effect this year.

Advocating for a Family Support Waiver started at least two years ago. This waiver is not only an autism issue but also a disability issue. The Advocacy Coalition was formed and the members are DelARF; The Arc of DE; DE Autism Society of DE; Lower DE Autism Foundation; CERTS; Easter Seals; PIC; UCP; Downs Syndrome of DE; and Family Voices. Coordinated efforts were not successful in getting the Waiver funded. However, the Advocacy Coalition decided to try again this year for funding. The Advocacy Coalition will be actively working at Legislative Hall with materials and testimonies to support this effort. So, if any of the organizations represented today would like to join the Coalition's effort, please do so by sending [Robdelautism@aol.com](mailto:Robdelautism@aol.com) an e-mail; or by contacting him on his home phone - 378-3462.

Tim added the Family Support Waiver is now called the Self-Directed Services Program Waiver under DDDS. Eventually, by 2010, it will serve the same number of people that the original waiver was supposed to be serving - 1398 persons. It is being funded in two ways by DDDS. Under the ARC lawsuit agreement, 75 residential DDDS placements per year were to be served. This number is cut back to 40 residential placements. The money from the residential placements will be used to help fund this waiver along with the dollar to dollar federal match. The drop in residential placements is a concern. However, due to budget restraints, there is no other way this waiver would pass. Another concern is that there was no increase in the budget for providers.

Susan added that her division has reduced the cost of kids going out-of-state for residential support by 58% by building up community support. Rob confirmed that their issues are wide open from cradle to grave. Susan added that Mark Eichler, a lobbyist and Executive Director for the Children's Campaign, may be a contact for Rob.

Kyle asked Tim about the Medicaid Rehabilitation services option impact. Tim stated that if DDDS did not fund the waiver, they would have lost approximately \$4.5 million dollars in federal funds because CMS is redefining "Rehab" option. A state can no longer use the Rehab option money for day programs. However, by implementing the waiver, DDDS will still be able to keep its federal funds.

### **Navigator Program**

Kamisha Martin from the Nehemiah Gateway-DE EITC, provided a hand-out and gave an overview on the 2008 DE Earned Income Tax Credit Campaign program.

The DE Earned Income Tax Credit program is a free tax preparation program provided to Delawareans with a household income of \$40,000 or less a year. This program helps those households get the Earned Income tax credit. Approximately 15-25% of the eligible population does not claim this tax credit. A total of 12,000 taxes were prepared with \$17 million being put back in the pockets of Delawareans. There are 22 tax sites this year throughout the state of DE. This program is partnering with the Navigator Program to see if they can do some targeted outreach to this population. If they are unable to come to a tax site, they can send their tax information into a site. Also, savings accounts can be opened; and savings bonds and CDs can be purchased at the tax sites. Free credit reports are provided. A hand-out of statistics on the Nehemiah Gateway 2007 campaign was provided to the Council.

Carolanne O'Brien stated that the U.S. Dept of Labor and Employment and Training has made it a Navigator goal to work with the IRS. This year we are helping by giving out all this information. Please take as many flyers and place out at churches, meetings, etc. The Mobile 1 stops going up and down the states will work with the volunteers to pass out this information at the service centers, etc. For interpreter needs, it was suggested that the Delaware Helpline be pro-active and take requests for interpreters ahead of time and also for requests for accessibility needs. The question of who is to pay for the interpreters needs clarification. For any student tax preparers or a cash coordinator, Wilmington University, the University of DE, and Delaware State University will give class credits. Kamisha will also find out the curriculum and give that information to Carolanne.

### **DPC Task Force Report**

Rita Langraf gave an overview of the Executive Summary which was provided to the Council.

The full task force report is on the website: <http://dpctaskforce.delaware.gov> and on Governor Minner's homepage.

The Task Force provided the final report to the Governor on December 19. When the task force met with the Governor and a representative from the Budget Office, they said that they will look at the recommendations and separate those that require a fiscal note.

The priorities to the members of the task force are:

- The ability to have an oversight mechanism to continuously review the operations inside of DPC primarily in the area of performance improvement. If this unit was enhanced, that would improve the quality of care. They learned that a lot of things were not being tracked or trended in any meaningful way in order to provide the administration with good information to advocate for any type of changes. The areas that they were able to track, but did not trend, were in the areas of restraints and seclusions. In a performance improvement area, they did very well at tracking; however, nothing came after the tracking – there were no conclusions while people were put in seclusion or restraints on an on-going basis. We advised them to use that trending and tracking for restraints and seclusions and take it to the next step and to look at medication errors. If more people in certain units are having these errors, it would help to identify the education and training unit levels of the staff of DPC. This was very well received and they are looking at ways to improve that unit.
- With regards to the DPC Oversight Committee, the DPC task force is recommending that this committee be established within the Governor's Advisory Council on Substance Abuse and Mental Health. Rita went before the Advisory Council and they did endorse the work of the Governor's Task Force and will be looking closer at that piece since they will be charged with that level of oversight. The House will probably be looking at legislation around that particular piece. Also, they supported the fact that the Disabilities Law Program has access to the PM-46s as they do in many other states to be a part of this Oversight Committee. Also the Governor was advised that it would be very beneficial to have a full department Mortality & Morbidity committee. Basically, this would look at how we can strengthen the system. For example, the medical care area could be addressed, and if there are gaps in certain areas, address those gaps. The Department was asked to look at the DSCYF, since it has worked well for them, and try to mirror off of them.
- With regard to enhancement in the community, from research, the community only gets enhanced when there has been a crisis at DPC. This cannot continue. If community mental health services were enhanced, the task force believed many people that are in the hospital could be in the community. There are about 245 people currently at DPC and the average aggregate stay is over 2,000 days while the national average is 869. There clearly needs to be assessment of the individuals who reside there as well as the assessment of the capacity of

community services. The Department should be looking at this on an on-going basis. Thirty-five people are going to be discharged from DPC by February 4. The providers have said that many of the 35 people that are going to be discharged did not know that they are going to be released. People need to be involved in this process; and this is not happening, at least from what Rita is hearing at the community level.

- Also, the Task Force is advocating for an experienced hospital administrator and consultant coach to be contracted. This was advocated for regardless of the fact that they have hired a hospital administrator. The task force believes that the Department, hospital administrator, hospital and patients could benefit from a consultant that could be here for six to eight months to support all efforts and lend expertise to the hospital. At this stage, it is not known if the state will move forward with this position.
- Provider contracts were recommended and the Department needs ensure that providers are adequately funded (including inflation).
- NAMI is looking at the report and creating a draft response to the task force report as well as the Legislative report. NAMI's concerns were incorporated in the task force report. Also, the Mental Health Association is also looking at the report. The Task Force has been disbanded as a body; but we believe that the work will continue to be advocated by many on the task force as well as community leaders.
- Another team within the Task Force looked at the building of a new facility. The task force believes that the current structure is very archaic and is unsafe and unhealthy. However, the task force did question why it is going to cost the state \$134 million and be serving 207 people. The Governor's budget supported the recommendation to do an actuarial study and to use a different consultant from the original one. A concern is that the Governor is recommending the need for \$1 million to plan a new psychiatric center. The task force will be analyzing this need.
- Also, the task force recommended to the Department to look at ways to build the community relationships with the current community hospitals in all counties. The task force believed that people from Sussex County should not have to relocate to get this level of care. The reason for the need for 207 beds was that Sussex County is primarily being hit with the aging population. It was recommended to revisit the service delivery and where that occurs so every county may have a higher level of service in psychiatric care.
- The Governor is also recommending \$500,000 for further improvements to the DPC. The task force would like to know how that fits into the recommendations that they proposed. In addition, the Governor is recommending \$2 million in community mental health to expand community based residential treatment by

adding three group homes with an additional \$450,000 for one supervised apartment. The \$2 million is to support the 35 that are exiting now on a 12 month basis. The additional \$450,000 would support a new group of possibly 10 people. The task force recommended 50 people a year should be transitioned and Rita does believe that the House report is supportive of this number as well.

- The wing where the 35 people that are currently housed, but will be transitioning, is closing. Jim Lafferty said that one concern is that there is a shortage of RNs. People are not applying for jobs because of the publicity and they do not want to work at the DPC. Contractors have to be brought in to staff. Rita said that they have hired an organization to help with the recruitment of staff. People from within have applied for the director of nursing. The Department of Justice will begin their investigation when the House Committee report is finalized. A consultant coach would be beneficial in these areas.
- Rita's request to the SCPD is to stay vigilant and voice what needs to be done. The House committee report will be out soon and Kyle will alert the council when this happens. The Council agreed it needed more time to research both reports. Kyle will send information on links to both reports to the Council. Member could then read the reports and this will be on February 25 meeting agenda. Rita will clarify some of the numbers to the Council in time for the Feb 28 JFC Hearing.

### **JFC Hearings**

Kyle addressed the JFC hearing schedule hand-out. The ones that the SCPD may have an interest in are as follows.

Feb 7 – Housing—10:30 am. Kyle will talk to Daniese about testifying. This will be a good time for some of the goals from the Governor's Commission/SCPD Housing Committee to be recognized.

Feb 12 – Child Mental Health—11 am. Rita added that one of the goals could be that after the age of 18 kids may need additional support transitioning into the adult system. Kyle noted that at our February meeting, Lou Bartoshesky will be at our meeting to talk about transition services from AI dupont Hospital. Kyle will talk with Susan to see if there is anything that she would like us to bring to the forefront. Rita reported that Susan also indicated they are looking at enhancing services for early intervention.

Feb 19 – DeIDOT—1 pm. Sunday Paratransit service is being supported which the SCPD has been advocating for a long time. Jamie will be testifying for the DD Council—so it would be good for Daniese to be consistent in advocating for this issue.

Feb 27 – DHSS – DMMA at 1:00 pm and DDDS at 2:30 pm. Brian will be testifying at the DDDS hearing.

Feb 28 – DSAAPD at 10 am and DSAMH is at 1 pm. Brian will be testifying at both hearings.

Kyle will contact Connie Hughes Director of DelARF to get a copy of their testimony and determine if SCPD wants to support their efforts regarding provider increases.

Wendy announced that the Governor's Council for Exceptional Citizen's budget hearing will be on Jan 29 at 2:30 pm—please come and support them.

### **Legislative Disability Awareness Day**

Wendy gave an overview of the two brochures regarding this event.

The hope is for people from the disability community to reach out to our legislators. Our hope is to have people come and support us this day in making contact with legislators and discuss any issues impacting them or any family members having disabilities. However, there will be talking points on priority issues.

For the Awareness Day, there will be a table on the second floor of Legislative Hall. The other part will be a training session from 9 am to 12 noon for 25 individuals. As of now, about 15 or 16 people have signed up for this training. We want the individuals to contact their legislators prior to the event. Joann Hasse from the League of Voters will be discussing how a bill becomes law and talking about the importance of voting. For about 30-45 minutes, Jamie and Daniese will be reviewing the talking points and letting people feel comfortable explaining to the legislators what they want to advocate for. Then, Representative Maier and Senator Henry will be speaking on how they feel it is best to contact your legislator and work with them to get goals accomplished at Legislative Hall. Please get the word out and join us and help us to reach out to our legislators to make a major impact.

Kyle added that this is taking the place of our Legislative Forum that was held in the past. If you have any questions, please contact Kyle or Linda.

### **Universal Design Coalition/Gubernatorial Forum**

These two issues were deleted due to time constraints.

### **CMS Proposed Rule for State Plan Option to Direct Personal Assistance**

Jamie Wolfe gave an overview on the e-mail in today's materials

CMS is proposing the attendant services program could become a state option through Medicaid. Right now there are no attendant services under the state plan. If this was added to the state plan, it would service a lot more people. It would allow individuals who are on Medicaid to have two choices---1) you could hire your own attendant to do personal care—they cannot provide medical care; 2) if you choose to use an agency or

hire your own attendant, the recipient would receive a cash allowance—for pay and benefits, etc. This is a proposed regulation and comments are due February 19.

Motion was made, seconded and approved for the SCPD to comment to CMS that we endorse the concept and encourage DMMA to support this concept as well.

### **PAS Update Report**

Tom Barlow has provided a spreadsheet on Personal Attendant Services and provided the following overview.

The total number served (year-to-date) of FY 08 Caseload Tracking is 86 persons.

After the last session, \$400,000 was added from the Tobacco funds to DSAAPDs to provide additional attendant services; specifically, to eliminate the waiting list for these services.

The next section on the spreadsheet “Participants with Relatives as Paid Attendants was addressed. Back on August 1, DSAAPD implemented as system for relatives to work as paid attendants. There was a 20% shift over to use relatives from current PAS users. With the new persons coming off of the waiting list, there is a much higher percent of 64%. For the most part, the people that had attendants in place had a work relationship in place over the years so they were not as likely to change. The new people who came on board off the waiting list had the option to hire relatives and used this option more.

The next section is tracking the Expansion. Originally, there were 27 people on the waiting list. Since the end of the last fiscal year, there were 23 other referrals. There were various outcomes—people declined the services when they learned more about it; people were removed from the list when they had gotten other services which canceled out the need; some people had changed so drastically in their care needs that they were in a long term situation, and some died. In the process, as of today, two people of the 27 do not have PAS hours. One will start soon and one has a bad credit rating which makes it hard to get a bank account (however, they are working with one of the main banks to make it happen).

In general the response has been good from people getting the service for the first time, particularly if they had been waiting for a year and a half. Right now, no more people can be served unless someone leaves the state or passes away. This is based on joint calculations between Easter Seal and DSAAPD on how many hours are committed and what it takes to get through the year. It is logical to think that the waiting list will build again so we will want to be asking for more funding for FY 10. What Jamie has mentioned about possible Medicaid funding would really make a big difference as well. Also, Tom heard that DSAAPD is preparing a RFP for these services and they have been working the last couple of weeks on revising the program specifications. Kyle stated that under the law, the SCPD is the advisory body for the PAS program. ; Tom assumed that



Kyle was aware of this RFP and revising the program specs. Kyle will contact Zel Cannon and copy other people involved and ask how the SCPD can become involved.

### **Action Item**

#### **Case Management Services for Medicaid**

Brian gave an overview/update on today's hand-out.

Last week Brian, Tony and Bob attended a DDDS Advisory Council meeting. Valerie Smith from DDDS mentioned a problem with an interim Medicaid regulation that restricts the scope of case management. Originally, the State thought that it would not apply to waivers; however, it does apply to waivers. Valerie asked that the Councils' submit comments in opposition. Brian drafted a letter for the SCPD addressing the following three issues: 1) the Medicaid billing will be required to less than 15 minute intervals. The argument against that is that the case manager will be spending more time on administrative time-keeping than on substantive case management. Also, it will result in an administrative burden on states since they will have to process invoices for services with numerous small entries; 2) this will limit case management to a single person. There is some advantage in having a single person responsible. On the other hand, it undercuts job sharing. Also, you could have complex cases in which you may have someone with physical and mental health needs which would benefit from co-case managers; 3) There will be limits on days that would be compensable by Medicaid with discharge planning work. So, if you are in an institution for 180 days, it would only be the last 14 days that you are in an institution. This would undermine the discharge planning process. Case management services of a longer duration should be allowed.

Motion was made, seconded and approved for the SCPD to write a letter to CMS with the above commentary.

### **Committee Reports**

Due to time constraints, the committee reports were deferred until the next meeting.

### **Announcements**

Tim sent Kyle an e-mail thanking everyone for the Lifetime Achievement Award that he received from the Council at the Life Conference. Kyle will send Tim's e-mail out to the Council.

Jamie announced that on February 21 from 3:30-5:30 pm there will be a training on Medicaid Buy-In at the U of DE Center for Disabilities Studies given by Jamie and Steve Groff. This training will look at eligibility, enrollment and history. This training is for professionals and consumers. If there is time at the training, there will be public input on the regulations. If there are a lot of individuals that would like training in Kent and

Sussex Counties, it can be provided. Jamie will be sending out flyers tomorrow. If anyone is interested in attending, please e-mail Jamie or Kyle.

**ADJOURNMENT**

The meeting was adjourned at 4:05 PM.

Respectfully submitted,

Kyle Hodges  
SCPD Administrator

SCPD/minjan08